Home-based palliative care:
challenges in the care of technology-dependent children

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Abstract

Objectives: To conceptualize palliative care and its indications in Pediatrics; to describe the difficulties involved in the delivery of such care at home for technology-dependent children; and to analyze, from a bioethical perspective, the moral dilemmas of palliative care assistance.

Sources: A literature review of palliative care for technology-dependent children and a bioethical analysis of moral dilemmas.

Summary of the findings: There are several obstacles to palliative care for technology-dependent children: structural difficulties at home; social isolation of both children and families; health professionals' sense of disbelief regarding this type of care; an excessive number of medical devices at home; uncertainty of a terminal prognosis; physical, emotional, social, material, and financial burden for parents and family; changes in family dynamics to adjust to these children; paternalistic relationship between professionals and family; changes in family roles, with shifts in the caregiver role.

Conclusions: It is essential to outline an agenda based on the premise that the medical apparatus for technology-dependent children will change the landscape of the home, and such a change might become a problem to be faced by all those living together. Based on this assumption, actions performed in a setting other than a health care facility might exert an actual protective effect on children and family, offering support in their several needs and developing a model of care delivery that includes interventions in the different levels of burden on these vulnerated and unprotected individuals.

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"*Caring should always take priority over curing for the most obvious of reasons: There is never any certainty that our illnesses can be cured or our death averted. Eventually they will, and must, triumph. Our victories over sickness and death are always temporary, but our need for support, for caring, in the face of them is always permanent.*"[1]

Introduction

The development and broad availability of palliative care around the world, within a concept of integrated, active and continued multidisciplinary care delivered both to patients with a terminal condition and their families, is very recent,

being formally introduced in 1967 with the foundation of St. Christopher's Hospice, in London.[2] This gave rise to the modern hospice movement, which, differently from the then known modern hospices, has integrated education and research into the health care field, turning St. Christopher into a worldwide center for developing and disseminating knowledge concerning palliative care.[3]

Particularly within the field of pediatrics, the availability of palliative care is even more recent. The first children's hospice (a facility designed to provide a caring environment for the terminally ill) was opened in 1982 in England (Helen House), and the first hospital delivering pediatric palliative care was the St. Mary's Hospital, in New York, with the pediatric

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palliative care unit being introduced in 1985 and closed in 1990.[4] Evidence on this recent growing interest comes from the first edition, in 2006, of the Oxford Textbook of Palliative Care (a reference textbook of palliative care), concerned specifically with the care of children and adolescents (Oxford Textbook of Palliative Care for Children).[5]

The growing challenges of implementing pediatric palliative care programs mirror the wide diversity of clinical situations – to be discussed further – which affect children and make them potentially eligible for this type of care, and most of these conditions require continued use of technology to keep these patients alive.

The expression "technology-dependent children" refers to those children who "need both a medical device to compensate for the loss of a vital body function and substantial and ongoing nursing care to avert death or further disability."[6] This concept has four characteristics: first, the need to use medical technology; second, only life-sustaining technologies are included; third, the dependence is assumed to be prolonged; and fourth, the need for highly technical nursing care skills. However, regarding the last aspect, it is worth noting that such care may be provided by nonprofessionals. Medical devices include the continued use of mechanical ventilation, or any other noninvasive ventilatory support; parenteral nutrition; peritoneal or renal dialysis; and use of intravenous drugs.[6] For the purposes of this article, we also included technology-dependent adolescents in this category.

It is important to highlight that most of these children have severe mental, emotional, and behavioral disabilities, making them totally dependent on continued care from their parents and family.

Data on the prevalence of technology-dependent children are scarce. In the late 1980s, the estimated number of technology-dependent children in the United States was 100,000.[6] In the United Kingdom, it was estimated that, in early 2000, there were approximately 6,000 children.[7] In Brazil, however, there are no national reports on the prevalence of technology-dependent children, but based on individual experiences we can infer that there is a significant absolute number of these children.[8]

Based on a literature review, we initially conceptualized pediatric palliative care and indicated the clinical conditions for which they might be used. After that, we analyzed the difficulties involved in the delivery of such care and some moral dilemmas of palliative care assistance at home for technology-dependent children.

Pediatric palliative care

A definition of children's palliative care is presented by the Association for Children's Palliative Care (ACT) together with the Royal College of Paediatrics and Child Health,[9] as follows: "palliative care for children and young people with life-limiting conditions as an active and total approach to care, from the point of diagnosis or recognition throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement."

A crucial distinction in planning interventions to be implemented at home concerns the concepts of "life-limiting conditions" and "life-threatening conditions". As follows:

- "Life-limiting/life-shortening conditions are those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration, rendering the child increasingly dependent on parents and carers."

- "Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as cancer. Children in long-term remission or following successful curative treatment are not included."[10]

The first conditions (life-limiting conditions) may be divided into four groups, as follows:[11,12]

- Group 1: Children with potentially curative conditions – for example, heart failure, liver failure, renal failure – and who may highly benefit from curative treatment, but disease progression may require concomitant palliative interventions or, depending on disease stage, as the main intervention model. Children in long-term follow-up (cancer remission) or recovering after successful treatment are not included in this group.

- Group 2: Children with chronic progressive conditions for which the use of technology, such as ventilatory support, may prolong life for long periods of time. This group includes neurological disorders, chronic lung diseases, and AIDS. For children with these conditions an integrated intervention model can be developed, one moment focusing on the curative model, and the next focusing on the palliative model, which tends toward prolonged duration, often lasting several years.

- Group 3: Children with life-limiting conditions extending over many years for which there is no curative treatment options, at least until the current stage of medical and scientific advances. This group includes mucopolysaccharidoses, muscular dystrophy, and neurodegenerative disorders, such as Batten disease. For these children, the primary objective should target palliative care assistance.

- Group 4: Children with severe, irreversible, non-progressive conditions, such as cerebral palsy and sequelae of spinal cord injury, but not terminally ill are likely to show complications leading to premature death. In such situations, treatment using technology may prove beneficial, but the

implementation of palliative treatment is often necessary. Treatment decisions rely on the expectations of the family and on the development, together with the family, of the most suitable intervention model for that particular case.

A survey of 632 pediatric hematology-oncologists in the United States investigated hospice referral practices for children with cancer and perceived barriers to referrals. Only a few respondents (27%) had access to inpatient hospice services, and only 45% of the hospices accepted children who were actively receiving chemotherapy. The majority (75%) of oncologists had no formal end-of-life training, and hospice referral was independently associated, in multivariate analysis, with increased numbers of new oncology diagnoses (odds ratio [OR], 1.8; 95% confidence interval [95%CI], 1.2-2.8) and the availability of a hospice facility (OR, 5.6; 95%CI, 2.4-13.3). On the other hand, the oncologists who reported employing chemotherapy and cited this continued therapy as the reason for not referring children to hospice had less access to a hospice that accepted children receiving chemotherapy. The study concluded that referral of children to palliative care programs is usually made late, and greater access to a hospice facility is crucial to determine the optimal moment for hospice referral, but this access is hindered because most hospices do not admit children receiving chemotherapy.[13]

This survey points out the importance of the continued education of pediatricians in end-of-life care and difficulties in referring children to pediatric hospices. In fact, access to pediatric palliative care programs and the effectiveness of these programs – most of them focusing on home care – have been highlighted as crucial to good practices in end-of-life care.[14]

Other barriers to be overcome in the delivery of good palliative care for children with life-limiting conditions concern: a) the sense of disbelief of several health professionals regarding this type of care and its purposes, particularly regarding enhancement of quality of life; b) shifts in the caregiver role, featuring a paternalistic caring environment, with an excessive number of medical devices; c) uncertainty of a terminal prognosis when an associated worsening occurs, often with previous history of recovery, when the child was expected to die; d) social isolation of both the children and families; e) physical, emotional, social, material, and financial burden for parents and siblings; f) changes in the landscape of the home and in family dynamics to adjust to these children, including the need to provide attention to the other, sick or healthy, children; and g) the relationship between the home-based palliative care team and the family.[15-17]

Home-based palliative care

Attention to patients and families at home is one of the aspects of the role of palliative care, which is particularly important when dealing with technology-dependent children, many of them with nonmalignant conditions. Some specific aspects that differentiate pediatric palliative care from palliative care for adults and the elderly are related to the full participation of family members in the care and to the duration of the relationship with the health care team, which might last several years.[18]

Consequently, daily nursing care services are transferred to these families – mainly the family caregiver, often the mother[19] – who becomes another "member of the team." Although this is a feasible practice, to our understanding, it is morally problematic. Caregivers are assigned operational and technical competences and responsibilities for which they have not received proper training, although the caregiver can develop such specific skills. Even when caregivers are health professionals, we believe that they should be considered as family members; although it may be helpful – since they hold a collaborative know-how – they should not be considered as team members. The aim is to avoid superposition of functions and, what could be more serious, the passive action of those who hold the necessary technical competence. Furthermore, the family caregiver's decision-making skills might be compromised by a protective feeling that can be explained within an environment of affectional bonds, where paternalistic behaviors are natural: the home environment. However, such behavior reproduced by the team members in this type of nursing care environment is potentially problematic and may limit the child's – in cases of cognitive competence – and parents' autonomy.

Paternalistic behavior might, therefore, come as a heavy blow to the constant exercise of rearranging decision-making processes, which are always difficult, but possible to be reasonably defined when there is the premise of an honest and careful dialogue based on the reality of the child's illness. This review of goals is a powerful antidote to a health care model that, over the time, runs the risk of becoming repetitive and static within a routine pattern pre-established by the team. The arrangement of routine activities in the adapted home, although playing a role in guiding the team and family members and meeting a concept of standardization of procedures, might restrain the way the services are delivered, leading to limiting and vicious procedures. Delivering palliative care requires, to our understanding, the exercise of a contradictory detachment from our technical know-how. By contradictory we mean that such know-how is essential to the practice of health care, but it should be at one moment employed, and the next discarded from the intervention possibilities. This behavior provides the professional engaged in this work the tools to understand and address, the best way possible, the anxieties and needs of the children and, more often, of the family.

Therefore, the key to a successful palliative home treatment lies in a good partnership between the health

care team, the children and the family, in an honest and friendly environment, in which the children, as much as possible, should be aware of their condition.[15,20,21]

The expression "home care" (HC) is used in this article in a broad sense, encompassing a variety of services delivered at home aiming at the patient's therapeutic support and assistance. It includes intimate care, drug administration, wound dressing, scar and ostomy management, and use of hospital technology at home: enteral/parenteral nutrition; dialysis; transfusion of blood-derived products; chemotherapy; antibiotic therapy; and respiratory support. For this purpose, 24/7 availability of medical and nursing services is necessary, as well as a support network for diagnosis and other therapeutic measures. This definition also implies a community-based support network (volunteers, community services, etc.).[22]

Caregivers of technology-dependent children experience considerable isolation, social exclusion, and feel overwhelmed and often physically and emotionally exhausted during their daily nursing activities, in addition to the significant material and financial burden on the families after diagnosis – which is often made in the patient's first months of life. Moreover, caregivers need guidance and information on the most relevant care to be delivered at home and should be able to rely on appropriate specialized support in the care involving high technology.[16,17,23-26]

This guidance should be developed in the hospital setting as part of a strategy of the often slow "weaning" process for both the child and family. Clear information on the child's illness, progress, potential complications and on how to manage care at home, in addition to assuring the family that they will not be abandoned, is an important tool to be provided to caregivers. Transfer from hospital to home needs to be careful and involves home visits and possible changes in home structure to receive the child. The adaptation required by all family members to this "different" child should be thoughtfully developed during this period and will take place over time by living together. However, the main point here should be the HC team's internal organization, which should be able to provide all necessary support and safety to this family.

The conflicting field of home care for technology-dependent children

Several studies have analyzed HC-related moral dilemmas, despite the potential benefits produced, mainly by health professionals and managers.[22,27,28] There are important studies showing the difficulties involved in delivering home-based care for technology-dependent children – among others, structural difficulties at home and difficulties in community acceptance –, although the impact of HC on the life of these children and their families is yet to be fully understood.[29-31] If these are considered significant

difficulties in developed countries, where the studies were conducted, in countries with considerable inequalities, such as Brazil, they become extremely important issues. This raises the question of which portions of the population will receive appropriate home care and which will either receive low-effective support or be excluded. This is a delicate surveillance issue of access, equality and resource allocation, which will require more creative solutions and commitment from managers rather than simple HC delivery adapted to ongoing circumstances. Another important aspect concerns the distinction between HC programs that simply overload nursing care at home from those that are concerned about quality of life and long-term outcomes of this type of care. Consequences in the field of pediatrics are obvious, since such care might extend over many years, giving rise to the need to outline an agenda of care that prioritizes the needs of the child and provides support to the family's burden. A review of the pre-established goals, in an environment of honest dialogue with family members and clear information on prognosis, may help to establish more realistic goals.[23,24]

It is equally important that family caregivers are offered alternatives (short breaks) so that they can have the opportunity to take care of themselves. An option is the provision of formal caregivers (professional caregivers), who from time to time could replace the family caregiver. In addition to these aspects, it is worth mentioning that due to technological advances these children are living longer and will be able to live longer and longer, probably for several years, that is, progressing into adulthood. However, similar to the children, their parents are aging and might get sick. This begs the question: who will care for these technology-dependent adults in the absence or illness of their parents?

We should also take into account potential HC-related problems concerning the use of technology alone: the configuration of a mini-hospital or an environment resembling an ICU are signs that the landscape of this home will never be the same. This HC model, which redesigns the home through life-sustaining technologies, bringing the hospital home – known as "hospital without walls"[32] –, although it seems a legitimate, promising alternative, sets up conditions to the "hypermedicalization" of the home[33] but without a homelike atmosphere, as often advertised by HC services.

One of the problematic outcomes of this model is a shift in the place of treatment that does not carry over a shift in the philosophy of the care provided.[22] From this perspective, it is important that palliative HC for technology-dependent children be not designed solely as an extension of hospital-based care, or as an escape for a manager that needs to pragmatically appraise difficult issues concerning resource allocation. On the contrary, it is important that this broad program be an integral part of a paradigm which sets up

conditions to change current models of care delivery, aiming, for example, to reduce the social isolation which these children and their families experience and to provide more suitable treatment options that meet reasonable criteria based on individual concrete cases. The program is also expected to set up conditions to support strong demands by overwhelmed and worn out parents, including significant material and financial losses.[16,19,34-38]

Conclusions

It is essential to outline an agenda based on the premise that the medical apparatus for technology-dependent children will change the landscape of the home, and such a change might become a problem to be faced by all those living together. Based on this assumption, actions performed in a setting other than a health care facility might exert an actual protective effect on children and family, offering support in their several needs and developing a model of care delivery that includes interventions in the different levels of burden on these vulnerable and unprotected individuals.

Therefore, the choice for the best life-sustaining technologies and the best models of care delivery should be made and agreed upon dynamic negotiations involving the children – whenever they have cognitive competence –, the HC team and family members, bearing in mind that these decisions will be made and accepted in an environment with important restrictions, such as the case of home-based palliative care for technology-dependent children. Finally, planning home-based palliative care programs should be based on the delivery of continued assistance, avoiding breaks from care. Although this aspect might sound difficult, it highlights the commitment of the manager to the protection of the children and their families. Although the Brazilian reality is somehow limited in that sense, in terms of planning a nationwide palliative care policy, the organization of health care services should contemplate full-time actions, that is, 24/7 availability of medical services. This is a necessary condition – although not sufficient *per se* – to the design of an actually effective and morally protective palliative care policy.

References

1. Callahan D. What kind of life: the limits of medical progress. Washington, D.C.: Georgetown University Press. 1990. p. 145.

2. Clark D. Originating a movement: Cicely Saunders and the development of St. Christopher's Hospice, 1957-1967. Mortality. 1998;3:43-63.

3. Monroe B, Hansford P, Payne M, Sykes N. St Christopher's and the future. Omega. 2007-2008;56:63-75.

4. Lenton S, Goldman A, Eaton N, Southall D. Development and Epidemiology. In: Goldman A, Hain R, Liben S, editores. Oxford Texbook of Palliative Care for Children. Oxford, Ne w York: Oxford University Press; 2006. p. 3-13.

5. Goldman A, Hain RD, Liben S. Oxford Textbook of Palliative Care for Children. Oxford: Oxford University Press; 2006.

6. Office of Technology Assessment. Technology-Dependent Children: Hospital v. Home Care - A Technical Memorandum, OTA-TM-H-38. Washington, D.C.: U.S. Government Printing Office; 1987. http://www.fas.org/ota. Access: 05/06/2009.

7. Glendinning C, Kirk S, Guiffrida A, Lawton D. Technology-dependent children in the community: definitions, numbers and costs. Child Care Health Dev. 2001; 27:321-34.

8. Drucker LP. Rede de suporte tecnológico domiciliar à criança dependente de tecnologia egressa de um hospital de saúde pública. Cienc Saude Coletiva. 2007; 12:1285-94.

9. ACT.org. [website]. Bristol: Association for Children's Palliative Care.org. http://www.act.org.uk. Access: 04/09/2008.

10. ACT.org. [website]. Bristol: Association for Children's Palliative Care.org. http://www.act.org.uk/act/definition.asp. Access: 04/09/2008.

11. The Association for Children with Life-Threatening or Terminal Conditions and their Families, The Royal College of Paediatrics and Child Health. A Guide to the Development of children's Palliative Care Services. Bristol: ACT. 2003. http://www.act.org. uk. Access: 04/09/2008.

12. Dussel V, Medin G. Pediatrics issues. In: Bruera E, De Lima L, Wenk R, Farr W, editors. Palliative care in the developing World: principles and practice. Houston: IAHPC Press. 2004. p.227-56.

13. Fowler K, Poehling K, Billheimer D, Hamilton R, Wu H, Mulder J et al. Hospice referral practices for children with cancer: a survey of pediatric oncologists. J Clin Oncol. 2006;24:1099-104.

14. American Academy of Pediatrics. Committee on Bioethics and Committee on Hospital Care. Palliative care for children. Pediatrics. 2000;106:351-7.

15. Graham R, Robinson WM. Integrating palliative care into chronic care for children with severe neurodevelopmental disabilities. J Dev Behav Pediatr. 2005;26:361-5.

16. Hunt A, Elston S, Galloway J. Voices for change: current perception of services for children with palliative care needs and their families. Bristol: ACT. 2003. http://www.act.org.uk. Access: 04/09/2008.

17. Wang KW, Barnard A. Technology-dependent children and their families: a review. J Adv Nurs. 2004;45:36-46. Review.

18. Thornes R. Palliative Care for Young People Aged 13–24. Bristol: ACT. 2001. http://www.act.org.uk. Access: 04/09/2008.

19. Thyen U, Kuhlthau K, Perrin JM. Employment, child care, and mental health of mothers caring for children assisted by technology. Pediatrics. 1999;103:1235-42.

20. Kirk S, Glendinning, C. Developing services to support parents caring for a technology-dependent child at home. Child Care Health Dev. 2004;30:209-18.

21. Sarvey SI. Living with a machine: the experience of the child who is ventilator dependent. Issues Mental Health Nurs.2008; 29:179-96.

22. Collopy B, Dubler N, Zuckerman C. The ethics of home care: autonomy and accommodation. Hastings Cent Rep.1990;20: S1-16.

23. Carnevale FA, Alexander E, Davis M, Rennick J, Troini R. Daily Living With Distress and Enrichment: The Moral Experience of Families With Ventilator-Assisted Children at Home. Pediatrics. 2006; 117: e48-60. http://pediatrics.aappublications.org. Access: 01/09/2008.

24. Levine C. Acceptance, avoidance, and ambiguity: conflicting social values about childhood disability. Kennedy Inst Ethics J. 2005;15:371-83.

25. Wang KW, Barnard A. Caregivers' experiences at home with a ventilator-dependent child. Qual Health Res. 2008;18:501-8.

26. Heaton J, Noyes J, Sloper P, Shah R. Families' experiences of caring for technology-dependent children: a temporal perspective. Health Soc Care Community. 2005;13:441-50.

27. Liaschenko J. The moral geography of home care. Adv Nurs Sci. 1994;17:16-26.

28. Floriani CA, Schramm FR. Atendimento Domiciliar ao idoso: problema ou solução? Cad Saúde Pública. 2004;20:986-94.

29. Beresford B, Oldman C. Housing matters. National evidence relating to disabled children and their housing. Bristol: The Policy Press. 2002. http://www.jrf.org.uk. Access: 07/06/2009.

30. Chamba R, Ahmad W, Hirst M, Lawton D, Beresford B. Minority ethnic families caring for a severely disabled child. Bristol: The Policy Press. 1999. http://www.jrf.org.uk. Access: 07/06/2009.

31. Kohrman AF. Chimeras and Odysseys: Toward Understanding the Technologically Dependent Child. In: Arras JD (editor). Bringing the Hospital Home: Ethical and Social Implications of High-Tech Home Care. Baltimore and London: The Johns Hopkins University Press. 1995. p. 53-64.

32. Koren MJ. Home care - who cares? N Engl J Med. 1986;314:917-20.

33. Arras JD, Dubler NN. Bringing the hospital home: ethical and social implications of high-tech home care. Hastings Cent Rep. 1994;24:S19-28.

34. Aday LA, Wegener DH. Home care for ventilator-assisted children: implications for the children, their families, and health policy. Child Health Care. 1988;17:112-20.

35. Johnson CP, Kastner TA, American Academy of Pediatrics. Helping Families Raise Children With Special Health Care Needs at Home. Pediatrics. 2005;115:507-11.

36. Carnevale FA, Rehm RS, Kirk S, McKeever P. What we know (and do not know) about raising children with complex continuing care needs. J Child Health Care. 2008; 12:4-6.

37. Murphy N, Christian B. Disability in children and young adults: the unintendend consequences. Arch Pediatr Adolesc Med. 2007;161:930-2.

38. Raina P, O'Donnell M, Rosenbaum P, Brehaut J, Walter SD, Russell D, et al. The Health and Well-Being of Caregivers of Children With Cerebral Palsy. Pediatrics. 2005; 115: e626-36. http://pediatrics.aappublications.org. Access: 01/09/2008.

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